

Utah State Plan

**for Alzheimer's Disease and Related Dementias:
An Action Plan for 2012-2017
SUMMARY OF GOALS AND RECOMMENDATIONS**

GOAL 1 A Dementia-Aware Utah

RECOMMENDATIONS:

1A: Raise broad public awareness of Alzheimer's disease and related dementias through culturally appropriate education campaigns

STRATEGIES:

1. Seek public, private, corporate and philanthropic funding for broad-based, statewide education campaigns
2. Partner with the Bureau of Health Promotion, Utah Department of Health, to establish a program with health resource guides devoted to Alzheimer's disease and related dementias
3. Collaborate with the Center for Multicultural Health, Utah Department of Health, to develop and disseminate culturally appropriate print, radio and television media campaigns for awareness of Alzheimer's disease and related dementias
4. Target Utah's unique challenges associated with reaching and educating caregivers in rural areas, Spanish-speaking, other non-English-speaking, and Native American tribal communities with specific initiatives to overcome barriers to services
5. Promote realistic and positive images of people with Alzheimer's disease and related dementias and their caregivers to overcome existing public stigma and misperceptions
6. Advocate adoption of the Alzheimer's Disease Early Detection Alliance (AEDA) of the Alzheimer's Association by businesses, faith-based organizations, and community service groups to spread awareness among their constituencies
7. Partner with the State Office of Education to offer curriculum in schools to educate young Utah citizens on the facts of aging with sensitivity to those with cognitive impairment and family caregiving
8. Educate and enlist the faith-based community as a key resource that can reach out to and support family caregivers
9. Heighten public awareness resources, such as the 2-1-1 information line, 24/7 Alzheimer's helpline, Area Agencies on Aging, Aging and Disability Resource Centers, veterans clinics, and the Center for Alzheimer's Care, Imaging and Research, and establish metrics of awareness with the Division of Aging and Adult Services

1B: Ensure that reliable, up-to-date disease and care information is disseminated

STRATEGIES:

1. Disseminate public education campaign messages through accessible websites, mobile apps, libraries, senior centers, and physician offices with standardized Alzheimer's disease and related dementia content
2. Assemble content for public awareness campaigns to address a wide range of issues and audiences, including, but not limited to:
 - Early warning signs and effective strategies for obtaining diagnosis, treatment and support
 - Cost of long-term care, limits of Medicare, personal responsibility, importance of financial planning, and the limits and availability of community resources
 - Information from the Centers for Disease Control and other reliable sources on behaviors that might lower the risk of developing Alzheimer's disease and related dementias
3. Develop electronic links within state-supported websites to ensure that reliable information from state agencies is disseminated
4. Provide state-approved forms such as Durable Power of Attorney for Healthcare, Physician Orders for Life Sustaining Treatment (POLST) and other documents with helpful instructions and Frequently Asked Questions at no cost to the consumer via public libraries, resource centers and easily accessible websites
5. Ensure information and educational materials are offered at appropriate literacy, language, and legibility (font size) for a diverse population

1C: Provide Utah citizens with the best evidence on how to reduce their own risk for Alzheimer's disease and related dementias

STRATEGIES:

1. Encourage a wellness agenda for Utah that includes a brain-healthy lifestyle, inclusive of exercise, nutrition, cognitive activity, and social engagement as key protective factors against Alzheimer's disease and related dementias
2. Promote the Healthy Brain Initiative: A National Public Health Road Map to Maintaining Cognitive Health developed through a partnership of the National Institutes of Health, AARP, the Healthy Aging Research Network of the Prevention Research Centers, and many others
3. Support the Cognasium (gymnasium for the brain) movement in Utah, which encourages Utah citizens to take personal responsibility for brain health and develop their own Individualized Cognasium Plan
4. Emphasize heart, brain, and physical benefits of healthy recreation, senior games, fitness in the park programs, multigenerational activities, service to community, healthy aging, and senior center programs
5. Target the higher prevalence of Alzheimer's disease and related dementias among older African-Americans and Hispanics – twice that of older whites –

through education on diabetes and high blood pressure, conditions more common in these populations, and known risk factors for dementia

1D: Coordinate standardized information throughout state and local governments

STRATEGIES:

1. Coordinate with the Division of Aging and Adult Services on a continuing role of the State Plan Task Force as an Advisory Group to meet systematically with state and local agencies to identify programs and services relevant to older individuals with memory loss and dementia, even if not currently so identified, and advise on how dementia awareness would enhance performance
2. Enlist state and local governments to facilitate customer training about memory loss, Alzheimer's disease and related dementias for employees of government units interacting frequently with patients and families, such as the Division of Motor Vehicles, Adult Protective Services, Area Agencies on Aging, Community Mental Health Centers and County Health Departments

GOAL 2 Health and Dignity for All with Dementia and Those at Risk

RECOMMENDATIONS:

2A: Engage in a public health approach to confront Utah's significant projected growth in Alzheimer's disease and related dementias

STRATEGIES:

1. Empower public health officials and health care providers to promote disease prevention by addressing risk factors such as caregiving, ethnicity, diabetes, and heart disease
2. Promote brain health initiatives to reduce risk factors, especially in ethnically diverse communities
3. Collect and use data to drive public health service development and delivery
4. Recognize caregiving as a health risk factor that warrants public health attention to incentivize health professionals to acknowledge and address the issue
5. Increase surveillance of incidence of Alzheimer's disease and the impact of caregiving through the Behavioral Risk Factor Surveillance System (BRFSS) and other surveys
6. Use available data to assist in program improvement, grant submissions, and implementation of Utah's Alzheimer's Disease State Plan

2B: Improve access to a timely diagnosis, differential treatment, and supportive services

STRATEGIES:

1. Encourage accurate and dignified diagnosis and proactive treatment, differentiating Alzheimer's disease and related dementias, and promote continuing medical education for physicians and medical practitioners
2. Promote use of the Medicare preventive service benefit for the detection of cognitive impairment, which commenced in 2011 under the Patient Protection and Affordable Care Act
3. Expand the application of the Utah Telehealth Network and increase the number of physicians certified in the Network to treat patients with cognitive impairment in rural Utah
4. Provide a statewide comprehensive resource database and directory that includes information about the range of medical and other providers, programs, and services related to diagnosis, treatment, and support for persons with dementia
5. Pursue federal funding for evidence-based replication projects, including U.S. Administration on Aging grants to states for development of a statewide "dementia capable," sustainable service delivery system

2C: Provide access to behavioral health services and person-centered in-home care that includes evidence-based, non-pharmacological interventions rather than more costly inpatient treatment.**STRATEGIES:**

1. Improve behavioral health services through the recruitment and specialized training of physicians, nurses, and therapists to provide such services for persons with dementia that are covered through Medicare, Medicaid, and/or private insurance
2. Ameliorate neuropsychiatric symptoms of persons with dementia cared for at home by enhanced training and support of family caregivers on effective behavioral interventions that are designed to modify such symptoms, reduce caregiver distress, and delay nursing home placement
3. Support the development of senior behavioral services commensurate with growth in long-term care and assisted living, including an outpatient geriatric psychiatry consultation program through collaboration of the Office of Higher Education and the Department of Human Services, Division of Substance Abuse and Mental Health, and expand board-certified geriatric psychiatric care in both the private sector and community mental health senior behavioral health services
4. Extend person-centered care in rural Utah with evaluations and consultations for persons with dementia and their family caregivers by dementia specialists and an outpatient geriatric psychiatry consultation program through the Utah Telehealth Network

2D: Secure the safety, independence, and mobility of persons with Alzheimer's disease and related dementias with appropriate responses and policies for each stage of the disease

STRATEGIES:

1. Develop a Utah endangered person advisory system through the voluntary partnership of law enforcement, broadcasters, media and community organizations in which cases are initiated by law enforcement and an investigation is made on the missing person's whereabouts immediately
2. Support widespread and early enrollment of those with memory loss who tend to wander in the MedicAlert+Safe Return™ program of the Alzheimer's Association and encourage the use of cost-effective cellular and GPS tracking technologies to enable families to prevent wandering
3. Address the unique transportation needs of persons in the early stage of the Alzheimer's disease and related dementias, improve driving cessation policies, and promote available resources such as the Alzheimer's Association Driving Resource Center (www.alz.org/safetycenter) and the National Center on Senior Transportation
4. Partner with Adult Protection Services, law enforcement, the banking industry, and the court system to recognize ongoing or potential financial abuse of elders with dementia, protect those at risk, and curb ongoing exploitation
5. Expand CIT training of law enforcement throughout the state on aging issues and identification of those with dementia, particularly, in early stage and with behavior disturbance

2E: Enhance the self-determination of persons with memory loss and mild dementia, and prevent financial exploitation and abuse

STRATEGIES:

1. Enhance self-determination by encouraging persons with dementia and their families to assess management of assets early with the help of elder law specialists or Utah Legal Services, effective draw-down of assets, and avoidance of costly court proceedings
2. Facilitate the independence of early-stage persons with dementia by improving public and private transportation options, working with mobility managers, and training transportation providers and drivers
3. Explore from multidisciplinary perspectives a justice center system for elder and vulnerable adults to ensure timely and appropriate prosecution of those who exploit persons with cognitive impairment
4. Support guardianship and conservator policies that align with national standards, that respect the rights and needs of persons with dementia, and that minimize the burden on families and the legal system
5. Employ health care provider and community agency education to encourage widespread and early use of advanced health care directives

2F: Implement a statewide strategy to coordinate, integrate, deliver and monitor long-term care and services

STRATEGIES:

1. Establish mechanisms to coordinate among state and local agencies, government departments, voluntary health organizations, and private long-term care providers to better serve the aging and disabled population. For example, promote cross-training and joint visits by state regulators, and identify more efficient and effective regulatory oversight
2. Create an integrated state long-term care financing approach that provides incentives for people to receive care in home- and community-based settings and enables Utah to retain and reinvest cost savings back into the state's long-term care infrastructure
3. Provide regular training to regulators on best practices in dementia care to improve consistency and continuity between settings
4. Prioritize funding for medical care and long-term services and support through alternative financing mechanisms such as expansion of the use of Medicaid waivers or "provider fees"

GOAL 3 Supported and Empowered Family Caregivers

RECOMMENDATIONS:

3A: Acknowledge and invest in the vital role of family caregivers with guidance on quality care and the best utilization of family financial resources throughout the disease course

STRATEGIES:

1. Support, fund and expand the availability of professional guidance to help family caregivers navigate and manage myriad safety and behavioral issues through an array of services such as caregiver assessment, care consultation, counseling, care management, respite care, support groups, assistive technologies and other effective interventions
2. Increase participation in educational programs among diverse caregivers through culturally and linguistically appropriate offerings
3. Secure foundation, corporate and nonprofit funding for effective statewide family caregiver training programs
4. Provide health education early in the disease through medical providers, voluntary agencies, and the Caregiver Support Program of the Area Agencies on Aging that includes information about disease course, services needed at different disease stages, and how they are paid for

5. Encourage the financial community to provide information about financial planning for chronic illness, the use of long-term care insurance, and other financial instruments
6. Partner with health insurance providers to ensure that medically appropriate dementia services are clearly identified and addressed in coverage statements and covered in policies, including those for younger-onset dementias

3B: Empower caregivers through a supportive network that is better coordinated, and by expanding affordable respite care

STRATEGIES:

1. Recognize and address the financial burden of caregiving and work to protect spouses from impoverishment at all levels of care
2. Encourage businesses and other workplace sites to offer family caregiver support services, e.g. flexible work hours, referrals and counseling through Employee Assistance Programs and other employee initiatives
3. Advocate for state and federal tax credits, similar to the child care tax credit, for frail spousal and working adult offspring caregivers paying for direct care services to encourage the use of early intervention and support services, such as adult day and respite care
4. Research, disseminate, and expand private insurance and cafeteria plans that coverage supportive services for caregivers such as adult day
5. Evaluate the reimbursement rate for adult day care service and provide recommendations to bring the current rate in line with the actual cost of providing the service, based on analysis of:
 - The efficacy of early-stage dementia day care to support independent functioning for as long as possible
 - The possible value of setting rates for different levels of day care, acknowledging unique needs of persons with advancing dementia
 - The effectiveness of adult day service as a less costly alternative to state and federally funded permanent residency in long-term care
6. Consider the potential reallocation of Medicaid dollars between home and community-based programs and nursing home care, and the expansion of 1915c waiver programs to provide additional home and community-based support to caregivers of home-dwelling persons with dementia as well as save state and federal dollars

3C: Ensure that all families have access to clinical post-mortem diagnostic services and tissue banking to invest in the future health of their families

STRATEGIES:

1. Partner with hospitals as part of their public service mission to provide access to high-quality postmortem diagnostic services for individuals with Alzheimer's disease and related dementias

2. Encourage family-centered biobanking and linkage with the Utah Population Database so families can develop their own family health history based upon genealogical medical and genetic records
3. Mandate the death certificate data include information obtained through postmortem diagnostic examinations

GOAL 4 A Dementia-Competent Workforce

RECOMMENDATIONS:

4A: Develop a dementia capable and culturally competent workforce that cares for older adults and persons with dementia throughout the continuum of care

STRATEGIES:

1. Support certification, licensure, and degree programs that encourage working with older adults and persons with Alzheimer's disease and their caregivers. Require a standard level of dementia sensitivity and disease education for all trainees in health-related fields at the student and residency levels
2. Partner with licensing boards to mandate continuing education on Alzheimer's and related dementias as a condition of license renewal for doctors, nurses, and other health professionals
3. Mandate competency-based training based on the Foundations of Dementia Care, developed nationally by the Alzheimer's Association and more than two dozen national organizations, for employees in various settings (e.g., hospitals, nursing homes, assisted living, home care workers, care managers, agency caregiver support staff, and social workers), recognizing there are different strategies for different disciplines, settings, levels of skill and licensure
4. Provide guidance to care managers, advocates, and providers on the Medicare benefit that reimburses for an annual cognitive exam
5. Encourage care providers to partner with multicultural coalitions as they develop "dementia friendly services" ethnically diverse clients and residents across the continuum of care, including adult day care, in-home respite, assisted living, long-term care, and specialized dementia care
6. Create financial incentives (through tuition assistance, loan forgiveness, housing subsidies, and stipends) to increase the number of health care professionals who pursue education and training in gerontology and geriatrics, and particularly, those who make a commitment to work in low-income, uninsured, rural, and ethnic communities with higher disease prevalence
7. Educate providers on the use of Medicare coding to reimburse physicians and allied health professionals for family conferences and care consultation that educate and support family caregivers, guide future decisions, and enhance the quality of medical care and support services

4B: Improve dementia care capacity and competency of primary care providers

STRATEGIES:

1. Explore, endorse, and disseminate dementia-specific curriculum and training programs tailored to primary care physicians, geriatricians, internists, general practitioners, physician assistants, and nurse practitioners
2. Create and disseminate an evidence-based set of guidelines for Alzheimer's and related dementias disease management to improve evaluation, treatment, care coordination, and follow-up support of the patient
3. Improve primary care practices by linking them to dementia care managers to coordinate care, manage individual cases, and supplement clinical care with resources on supportive services and community-based agencies that offer specialized expertise, social supports, and mental health services
4. Train nurses, counselors, health professionals and direct care workers to develop person-centered one-on-one care to dementia patients of color and their families
5. Protect and promote Utah's Center on Alzheimer's Care, Imaging and Research as a tertiary referral resource for the state's physicians to support diagnosis and management of complex cases
6. Incorporate Alzheimer's educational materials for patients and family caregivers into digital libraries to enable physicians to store and disseminate such information in connection with electronic medical records
7. Educate clinicians on the criteria needed to refer and qualify dementia patients for hospice care to ensure that patients receive full benefit of the medical, health services, and social supports offered at end of life

4C: Train professionals in other, non-health care fields that interface increasingly with persons who have dementia

STRATEGIES:

1. Educate law enforcement on the MedicAlert+Safe Return™ program of the Alzheimer's Association to quickly identify and return to safety persons with Alzheimer's or related dementias
2. Support efforts of adult protective officials on detecting, addressing, and preventing fraud, abuse, neglect and self-neglect of persons with dementia in the community or in institutions of care
3. Partner with state regulators, court administrators, and the Utah Bar Association for training on legal issues facing persons with Alzheimer's and related dementia and their families such as guardianship, conservatorship, powers of attorney, and the medical standards related to each
4. Provide comprehensive Alzheimer's and related dementia training to first responders, law enforcement, EMT, fire fighters, emergency preparedness, and search and rescue officials

GOAL 5 Expanded Research in Utah

RECOMMENDATIONS:

5A: Recruit and retain world-class researchers, and attract research investments that generate economic multipliers to create jobs and drive innovation

STRATEGIES:

1. Collaborate with industry and the life and biosciences sector to increase research infrastructure
2. Ensure that the most promising evidence-based research projects are advanced and made sustainable, including research on prevention, treatment, and finding a cure for Alzheimer's disease
3. Promote research focused on the development of assistive technology, including both high and low tech assistive devices that adapt everyday environments for people with Alzheimer's
4. Engage community physicians in research toward early recognition of memory problems as well as other dementia symptoms, and rapid referrals to clinical trials

5B: Hasten development of promising new treatments with increased patient research participation and more federal, state and private research dollars

STRATEGIES:

1. Promote taxpayer contributions through a tax check-off to support Alzheimer's disease and related dementia research at Utah universities as administered through existing mechanisms at the Utah Center on Aging
2. Educate the public on the availability, purpose, and value of research, and encourage participation in clinical trials and other studies. Promote the Alzheimer's Association's TrialMatch™ as a resource for increasing participation in clinical trials
3. Collaborate with private, state, and federal partners to increase participation of diverse populations in research studies
4. Encourage the Utah Science Technology and Research (USTAR) Initiative to support a new investigative team in neurodegenerative disease at the University of Utah
5. Generate rapid commercialization and spin-off companies based upon promising and innovative dementia research at Utah universities through their Offices of Technology Development and industry partnerships
6. Collaborate with private, state and federal partners to increase participation of diverse populations in research studies